Challenges with Sharing Public Health Information Through a Health Information Exchange

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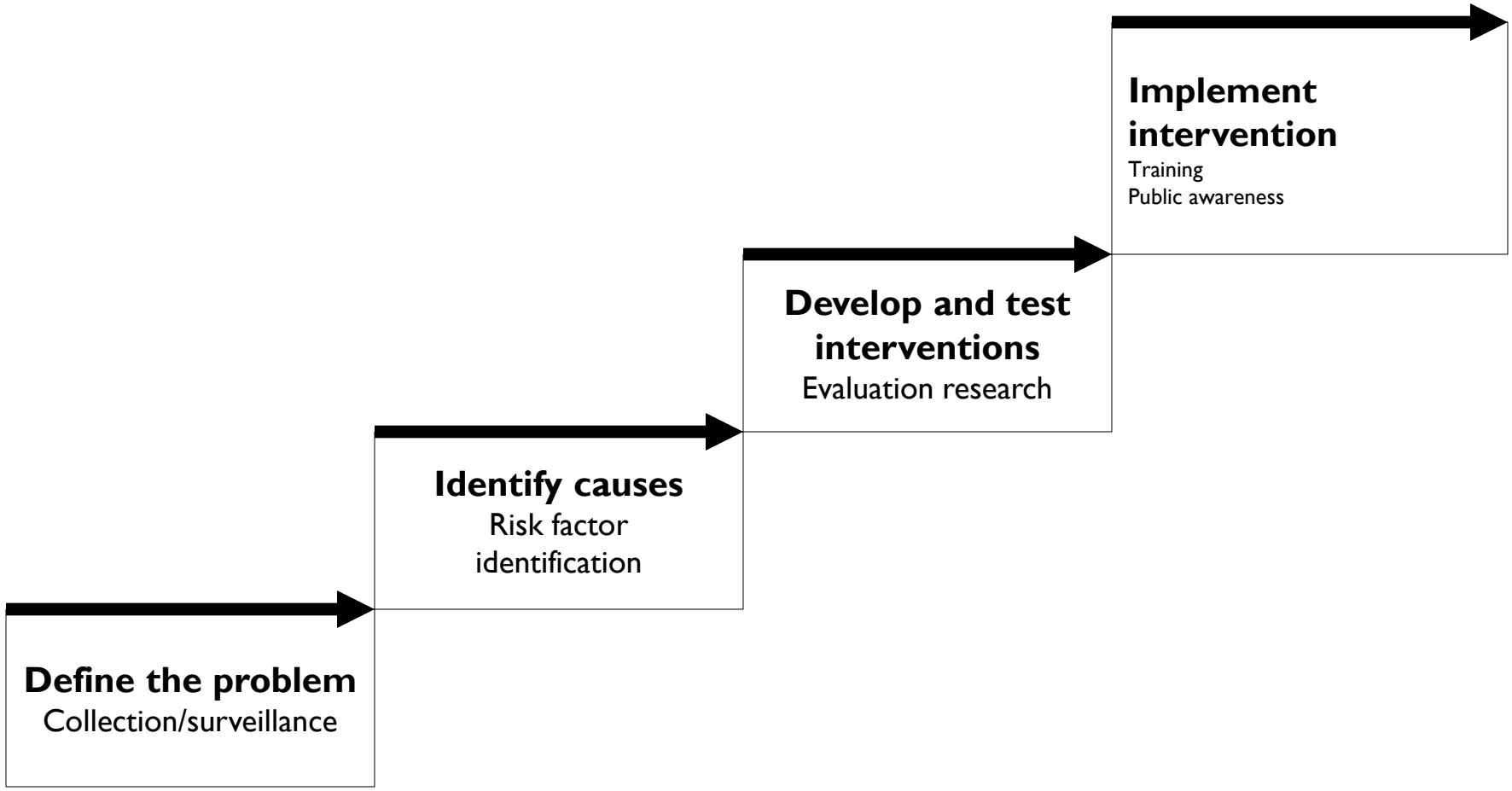
What is PH surveillance?

- Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health-related data …[to]…
  - Prevent or control disease or injury,
  - Identify unusual events of public health importance, and
  - Disseminate and use information for public health action.

  - Lisa Lee et.al., Am J Prev Med 2011; 41(6):636-640

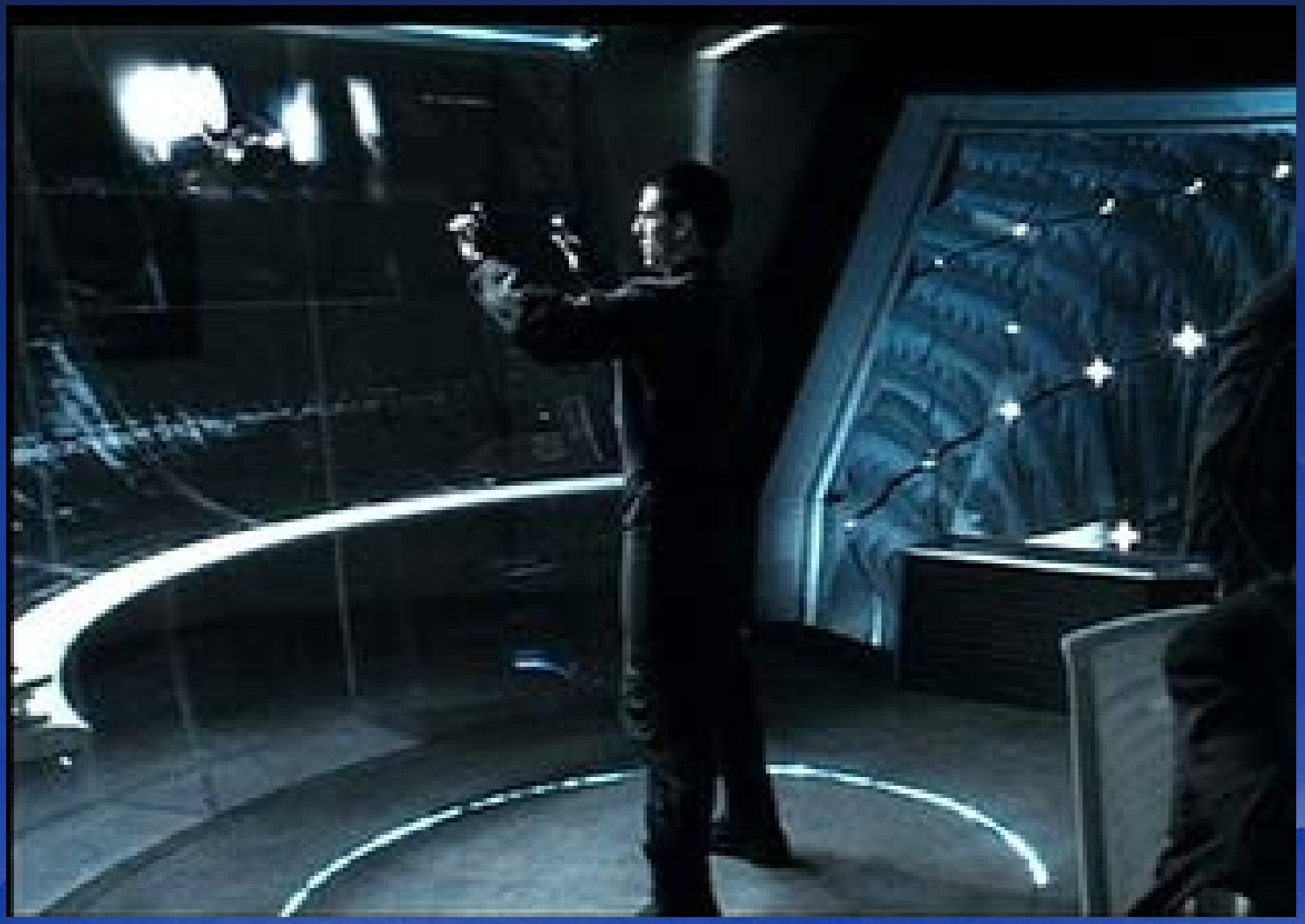
Public Health Model



We need to move from Sherlock Holmes

To the Matrix

Combined with The Minority Report



How do we get there?

- Public Health Informatics
  - Public Health Informatics has been defined as the systematic application of information and computer science and technology to public health practice, research.
- Need for Epidemiology trained informaticists
- Effectively and efficiently using technology to improve data collection and surveillance

Why is this important?

- Initiatives such as
  - Meaningful Use
  - Electronic Lab Reporting (ELR)
- Proliferation of EMR systems
- Need to do more with less

Computers have made us somewhat more efficient and timely, but

- Data is relatively poor quality
- Limited data analysis and interpretation
- Lack of coordination among LHD/State and Feds

Public Health Data

Neolithic revolution

Petabytes of data

- 1000 Kilobytes = Megabyte
- 1000 Mb = Gigabyte
- 1000 Gb = Terabyte
- 1000 Tb = Petabyte

- Expectation that electronic data exchange will process hundreds of petabytes of data daily

Current State/local Challenges:

- Current and projected large increases in volume of lab and case reports from healthcare (estimated increase 400-500%)
  - Data deluge
- Maintain and upgrade surveillance systems with limited PH resources
- Reduced funding = fewer staff
- Need new approaches for data management, analysis, and visualization

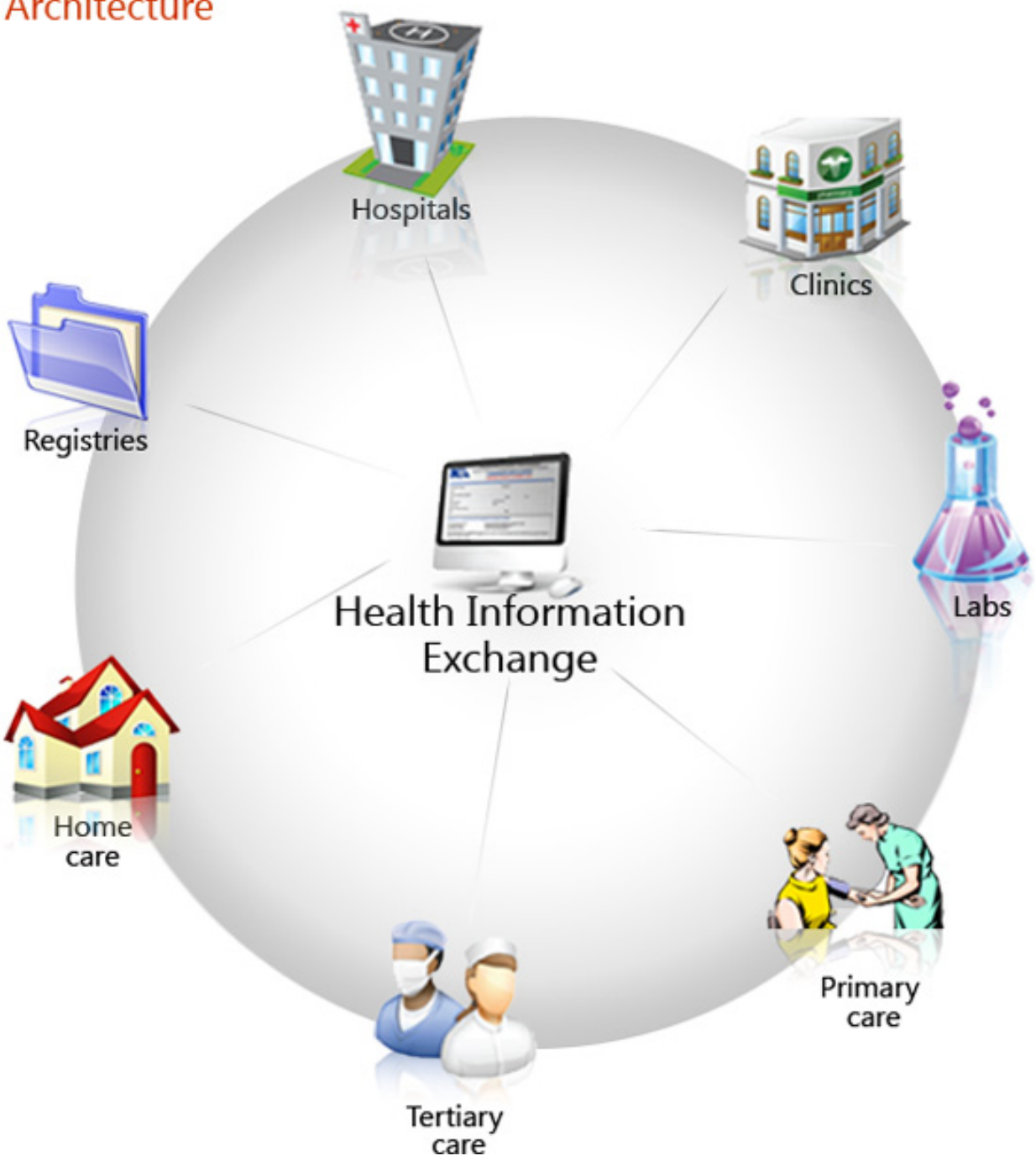
Current Federal challenges:

- Reduced funding = fewer staff
- Lack of interoperability/standardization
  - Use of same case definitions
  - Collect same data elements
  - Pendulum swing away from state/local autonomy
- Silos of data
- Goals of surveillance are different at local, state, and federal levels.

Health Information Exchange (HIE)

- Process of reliable and interoperable electronic health-related information sharing conducted in a manner that protects the confidentiality, privacy, and security of the information

Architecture



Domains for use of an HIE in Public Health

1
- Mandated reporting of laboratory diagnoses

2
- Mandated reported of physician-based diagnoses

3
- Public health investigation

4
- Disease-based non-reportable laboratory data

5
- Antibiotic-resistant organism surveillance

6
- Population-level quality monitoring

Benefits of using an HIE

- Single interface for multiple facilities
- More control of detection rules
- Potentially more standardization of vocabulary
- Large amount of clinical data
- Aids in investigation
- Current patient contact information

Challenges with using an HIE

- HIE first priority is to support clinical exchange
- Differences in coding/vocabulary
  - Same code may be used for different tests
- Data availability
  - Lag in sending data to HIE from EHR system
- Patient consent issues
  - Where does filtering occur?
- Cost to providers to use HIE for reporting?

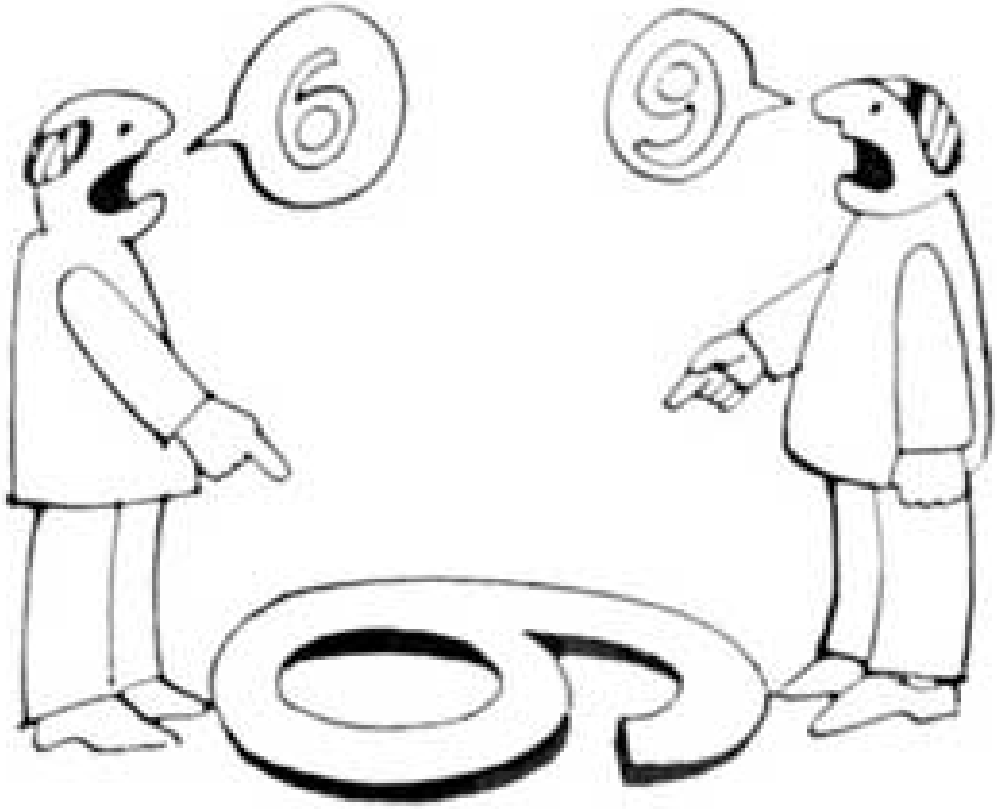
HIE first priority is to support clinical exchange

- HIE will code based on volume, not what is reportable
  - ie, CBC, chemistries, cholesterol, etc..
- Public health is generally a lower priority, so changes will take longer

Differences in coding/vocabulary

- Not all codes are equal
  - Incorrect codes
  - Different codes for same test
- Vocabulary issues
  - Different uses for same vocabulary by different facilities
- Many different ways to say the same thing

Interoperability



Standards and Interoperability

- Standards – the use of a vocabulary with unambiguous meaning between two entities (ex: case definition that says the patient must have a "fever"; lab report that defines a specimen as "S")
- Interoperability – the ability for two entities to exchange data with unambiguous meaning.

Vocabulary versus Structure

- Vocabulary refers to the meaning of the message part.
- Syntax or structure refers to the order in which the message was sent
  - I knew a man with a wooden leg named George
  - I almost wrote a check for $1000
  - I wrote a check for almost $1000

Data availability

- Facility may batch import data to the HIE
  - Immediately reportable conditions may be delayed
- Some facilities may participate in the HIE and other may not
  - Incomplete record or lab/clinical findings
- Data retention/removal policies
  - How long is data available

Patient consent issues

- Is there an opt-in or opt-out policy?
- Who manages consent
  - Centrally at the HIE
  - Locally within each facility
- When consent is changed are all stakeholders notified
- Where does data filtration occur?

Data filtration

- Can occur at:
  - The sender
  - The trusted third party (e.g. HIE)
  - The receiver
- Handshakes?

Costs of using HIE for reporting?

- Cost related to:
  - Money
  - Time
  - Data quality
- Costs to providers or public health
- The benefit of using the HIE must outweigh burden of independent interfaces

Case Investigation

"Your recent Amazon purchases, Tweet score and location history makes you 23.5% welcome here."

Vision

- Automated acquisition of primary investigation data
- Cloud data
- Reduced investigator workload
- Probabilistic determination of who gets investigated

- Data collection becomes ability to evaluate data streams, select appropriate streams, and merge them
- Use probability determinations to determine if we investigate a case
  - Pertussis – DFA (5%), PCR (40%), cough (10%), current vaccination (-20%)
  - 50% threshold for investigation

Challenges

- Accuracy
- Integration of investigation data
  - Data standards
  - Linking data (think changing addresses)
- Master patient index
- Temporary technology means mandatory changes in process
- Data ownership and control
- Possible loss of creativity

Data collection

- It costs money to collect and store data!
  - Vision is to do neither!
  - Shop at Costco, let others do the fishing and hunting and
  - Goal should be to eliminate data collection/storage as a public health function

Take-away

- Engage HIE early
- Encourage facilities to join HIE to ease burden of reporting requirements
- Make sure codes important to public health are included in the HIE mapping tables
- Increase infrastructure in public health to handle increase of data
- Train more epidemiologists in informatics

Resources

- AMIA 10x10
- *CSTE Scholarship* for Public Health *Informatics* Online *Certificate* Program
- Public Health Informatics Institute (PHII)

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Thank you

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